

**INDIANA'S COMPREHENSIVE STATE PLAN  
TO GUIDE SERVICES  
FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS**

**Indiana Autism Coalition, Inc.  
Autism Society of Indiana**

**February 2007**

## Foreword

Indiana Code 12-11-7-5(3) specifies that the Indiana Commission on Autism shall “Oversee and update the development of a comprehensive plan for services for individuals of all ages with autism.”

The first such document was completed in 1982 and updated in 1987. The 1987 annual review of the plan states, “The original document drafted in 1982 was not implemented by agencies, as there was no responsibility assigned and the document was large and cumbersome. However, the efforts of the first participants are what have made this document possible.” The authors of this report stress that responsibility was assigned, outcomes were planned and evaluation criteria were established in that initial document. However, limited results were reached and there are no records of any documents later than this 1987 version.

When the absence of a current, effective comprehensive plan was brought to the attention of the Indiana Commission on Autism during the 2005 interim, the Commission directed the Indiana Family and Social Services Administration (FSSA) to serve as the lead agency to oversee the creation of a new document. FSSA contracted with the Indiana Autism Coalition, Inc., to plan and execute a statewide survey of families living with ASD and providers serving those families, and to use the information gathered during this process to develop an updated plan. A collaborative team of individuals from the Indiana Autism Coalition and the Autism Society of Indiana (hereinafter “the team”) was established.

The team held stakeholder meetings at eleven locations throughout Indiana encompassing urban, suburban and rural areas to gather information via survey instruments developed specifically for this purpose. In addition, they interviewed family members, educators, service providers, and local and state agencies who serve families and individuals with ASD, and researched agencies and consumer organizations in a number of other states to determine best practices in use across the U.S. The results of those meetings, surveys, interviews and research were compiled and aligned with the *Autism Spectrum Disorders (ASD) Roadmap*.<sup>1</sup> The *Roadmap* was written by a group established by the Interagency Autism Coordinating Committee, created through The Children’s Health Act of 2000.

During the twenty years that have elapsed since 1987, the diagnostic criteria for ASD have been revised and expanded and the incidence of ASD has vastly increased. In addition, there has been an insufficient recognition of the long-term effects on Indiana’s medical and educational institutions, social services, and, most importantly, family systems. This has led to under-funded supports, misinformation throughout the community about ASD, and families who are forced to turn within and attempt to provide treatment and therapy on their own.

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<sup>1</sup> Sue Baker, Margaret Bauman, Maggie Bishop, Nancy DiMauro, Gay Finlayson, Sherry Glied, David Holmes, Chris P. Johnson, David Mandell, Gary Mesibov, Scott Myers, Cathy Pratt, Beth Roy, Ilene Schwartz, Stephen Shore, Stuart Spielman, Fan Tait, Amy Weatherby, *Autism Spectrum Disorders (ASD) Roadmap* [report on line] (Silver Spring: Maryland, Social & Scientific Systems, 2005, accessed 2 December 2006); available from <http://www.nimh.nih.gov/autismiacc/asdroadmap.pdf>; Internet.

To avoid the projected financial and social impact that could occur if these effects continue to be neglected, a commitment must be made to put into action the following recommendations. The authors of this report suggest to the Commission on Autism the creation and support of an independent interagency ASD coordinating council to oversee the statutorily mandated interagency cooperation agreement<sup>2</sup> and ensure the implementation of processes necessary to make these supports available to individuals and families living with ASD in Indiana.

Indiana's comprehensive plan (hereinafter, "the comprehensive plan") is presented in the following document along with other information and resources which support the findings. The comprehensive plan is designed to be a document which guides change in how individuals with ASD and their families are supported in the state of Indiana. The information presented comes from citizens within the state and speaks to their everyday experiences. It is with hope for the future of individuals with ASD and their families that this report is presented.

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<sup>2</sup> (IC 12-11-7-6) Sec 6. "The comprehensive plan required by section 5(3) of this chapter must include an interagency cooperation agreement among the following:

- (1) The department of education.
- (2) The division of mental health and addiction [of the Indiana Family & Social Services Administration (FSSA)].
- (3) The division of family resources [of FSSA].
- (4) The division [of disability and rehabilitative services of FSSA].
- (5) The department of child services.
- (6) Any other appropriate agencies.

## Acknowledgements

Indiana's Comprehensive State Plan to Guide Services for Individuals with Autism has benefited greatly from the generous assistance of the following:

Peter Bisbecos, Indiana Family and Social Services Administration  
Robin Cline, Hillcroft Center  
Diedra Conner, CPA, Evansville ARC  
Nancy Conner, BCSC Special Services  
Amanda Cooper, Johnson County Autism Support Group  
Sally Reed Crawford, M.A., Noble of Indiana  
John Dickerson, The Arc of Indiana  
Kim Dodson, The Arc of Indiana  
Gary D. Collings, Ed.D., ISEAS Project  
Teresa Grossi, Ph.D., Center on Community Living and Careers  
Brian Ketzner, Indiana Resource Center for Autism  
Tatia Korpenter, A Work in Progress  
Robert Marra, Ed.D., Indiana Department of Education  
David McIntosh, Ph.D., HSPP, ABPP, Ball State University  
Sally Morris, The Arc of Indiana  
Louise Lord Nelson, Ph.D., Reliable Alliance in Special Education, Inc.  
Alison O'Mally, Alternative Interventions Support Group  
Kim Opsahl, INARF  
Cathy Pratt, Ph.D., Indiana Resource Center for Autism  
Kris Prohl, Arc BRIDGES  
Debra Seman, ARC Opportunities  
Naomi Swiezy, Ph.D., HSPP, Christian Sarkine Autism Treatment Center  
Felice Vargo  
Joya Ware, Arc BRIDGES  
Marci Wheeler, M.S.W., Indiana Resource Center for Autism  
Ameilia Williams, Rauch Inc.

## **Recommendations for Achieving Successful ASD Services in Indiana**

The following recommendations are based on feedback provided via surveys which included one-on-one interviews with family members, individuals with ASD, service providers, and community supporters throughout Indiana. In addition, an extensive review of state reports from across the country provided comparison information. The recommendations are purposefully brief and focus on single issues. The intent is that this document will be used by an independent interagency ASD coordinating entity established by the Indiana Commission on Autism to monitor current support mechanisms and systems and to establish new practices and incentives at all levels of service delivery.

The first section provides a detailed list of suggested appointees to the independent interagency ASD coordinating entity. Sections II - VII are titled and presented in the order they appear in the *Autism Spectrum Disorders Roadmap*.<sup>3</sup> In addition, these sections are introduced utilizing the goals presented within the *Roadmap*.

### **I. Interagency ASD Coordinating Council**

**Establish an Interagency ASD Coordinating Council or other entity to determine service gaps and establish benchmarks for achieving goals set forth in this plan. The Interagency ASD Coordinating Council should be appointed by, and responsible to, the Indiana Commission on Autism and should include but not be limited to these entities:**

- Individuals with ASD
- Family members
- Indiana Department of Education/Division of Exceptional Learners
- Clinical, university-based, and other entities focused on autism research and supported through IDOE/Division of Exceptional Learners grant projects
- Indiana Resource Center for Autism
- Autism Society of Indiana (or the leading autism advocacy organization in the state)
- Office of Medicaid Policy and Planning
- Division(s) overseeing Aging and Vocational Rehabilitation
- Department of Mental Health and Addiction
- Department of Corrections
- Division of Children
- Department of Health

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<sup>3</sup> Baker, *Autism Spectrum Disorder (ASD) Roadmap*.

## II. Family/Professional Partnerships

**Goal: All individuals with ASD and their families will have a well-established, trusting, and mutually respectful relationship with a healthcare professional (medical home) who listens and responds to concerns, and who acts as an equal partner in providing a clearly defined plan of coordinated services.**<sup>4</sup>

- Increase and ensure continued funding for IDOE initiatives which provide ongoing training and technical assistance for professionals and families to engage as full partners.
- Ensure universities see the urgency/benefit of increasing ASD education in their professional development and general curriculums, especially as it relates to educators, medical professionals, and social workers.
- Increase funding through federal and state grants to increase capacity for ASD information and education resources at state and local levels (consumer advocates, university collaborations, state agencies).<sup>5</sup>
- Investigate solutions to improve capacity of rural areas in Indiana to address screening and treatment.
- Integrate ASD into existing initiatives to strengthen family support and involvement and establish integrated systems of care (e.g., DMHA Transformation Workgroup, IDOE Children's Social, Emotional and Behavioral Health Plan, Medicaid waivers, small business insurance plans, etc).<sup>6</sup>
- Encourage legislative approval of and funding for IDOE Children's Social, Emotional and Behavioral Health Plan.<sup>7</sup>
- Support current agencies, university programs, and clinical programs that offer conferences, resource/referrals, and family training programs.
- Establish buy-in from IDOH and FSSA to recognize value in agency-wide training around ASD.<sup>8</sup>
- Expand the systems of care being established in Indiana to include individuals with ASD.<sup>9</sup>

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<sup>4</sup> Baker, *Autism Spectrum Disorders (ASD) Roadmap*, 6.

<sup>5</sup> "We cannot financially afford with current funding to adequately serve children with autism, and we cannot as a community afford not to." Educator Survey, 2006.

<sup>6</sup> "As a consultant, I am spread really thin. There could be several positions similar to mine. We do not have a behavioral therapist/consultant due to funding." Educator Survey, 2006.

<sup>7</sup> "We need more education in school systems on autism and those disabilities. School teachers etc. need to be able to educate their students and families on resources; applying for a waiver the student's senior year is too late! Providers and direct care staff need training so we are not setting individuals up to fail." Provider Survey, 2006.

<sup>8</sup> "[Re seamless services] There are a lot of "break-downs." Provider Survey, 2006.

<sup>9</sup> *Funding for residential placement*: "We were asked to file CHINS in order to get funding for residential placement of our son. Although he certainly qualified, he was turned down (probably because DFS knew another government branch would step in with funding). We are glad he was turned down because we were told by a local lawyer that

### III. Early and Continuous Developmental and Medical Screening for ASD Responses

**Goal: Universal early identification of signs of ASD, followed by appropriate referrals to a coordinated and comprehensive service system.<sup>10</sup>**

- Support IACC Screening Council efforts to increase public awareness and incorporate ASD into routine screening.
- Promote the existing CDC awareness program, “Learn the signs. Act early,” through an IDOH initiative.<sup>11</sup>
- Ensure that state service providers are trained in routine ASD screening, especially in First Steps, Juvenile Justice, Community Mental Health Centers, Foster Care, Head Start Programs, and Health Centers/Clinics.<sup>12,13</sup>
- Continue IDOH collaboration with pediatric associations for pre- and in-service training and educational conferences.<sup>14</sup>
- Look to ASI, IDOH and other recognized partners to be conduits for distribution of materials about the national guidelines for ASD screening, diagnosis, and referral for follow-up as they are developed.<sup>15</sup>
- Increase state funding for and seek grant monies from federal initiatives to improve and standardize developmental and ASD screening methodologies.<sup>16</sup>

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had he been designated CHINS-6, guardianship would have gone to the state (even though Indiana state statute says this cannot be required—our local judge requires it or won't grant CHINS-6). After giving guardianship to the state, this local judge then requires full financial disclosure of family resources and assigns a monthly support payment. We were asked for financial information during the CHINS-6 process and refused. We were told there is no pre-set sliding scale to determine financial responsibility, that it was up to the discretion of the judge.” Consumer Survey, 2006.

<sup>10</sup> Baker, *Autism Spectrum Disorders Roadmap*, 8.

<sup>11</sup> “[Doctor] stated wouldn't diagnose any child as autistic before age seven. [Referrals not provided] until we insisted on treatment.” Consumer Survey, 2006.

<sup>12</sup> “He was in First Steps but they told us he was “OK” and didn't transfer us to the school system . . . I got him diagnosed myself at Riley when he was three years two months.” Consumer Survey, 2006.

<sup>13</sup> “Satisfied with therapy services, however we had three professionals that worked with him weekly for about one year but didn't realize there was more going on than DD. He was “graduated” out of services around two years—we got our autism diagnosis one year later.” Consumer Survey, 2006.

<sup>14</sup> “[Doctor thought he was] too young to decide even when he was assessed moderate/severe at age two on CARS scale for autism assessment.” “Child hasn't been diagnosed—school evaluated him. Therapy thru schools is very minimal, additional therapy is too expensive.” Consumer Survey, 2006.

<sup>15</sup> “[Our school is] struggling to adequately serve children with autism; [I am] comfortable speaking up but frustrated due to lack of money to do all I'd like. My biggest frustrations (besides huge numbers of kids arriving identified with autism): (1) lack of money (reduces our number of staff, OT & SLP; reduces opportunities to try other methodologies/use outside resources); (2) classroom teachers who are not well trained in a variety of methods; (3) trouble with difficult advocates where focus is not on kids—good advocates can be tremendously helpful, but bad ones hurt the process.” Consumer Survey, 2006.

<sup>16</sup> “Functional behavioral plan not typically done at preschool level.” Provider Survey, 2006.

- Incorporate ASD guidelines into curriculum for residency, professional certification, and other pre- and in-service medical training programs at all state universities. If this is not accomplished on a voluntary basis, consider legislative action.<sup>17</sup>
- As part of the transformation of DMHA, promote collaboration between existing state and consumer resource networks for developmental, educational, rehabilitative, social, and specialty services for ASD.
- Require IDOH crisis call center employees to receive training in ASD screening.
- Increase state budget to provide technical assistance and disseminate educational materials, checklists, implementation tools for ASD screening to families and professionals through university, clinical, advocacy, and other consumer organizations.

#### **IV. Access to All Needed ASD Health, Mental, Education and Social Services**

**Goal: Individuals and families with ASD have ready access to integrated and coordinated health, mental health, education and social services provided by well qualified ASD providers throughout the life cycle.**<sup>18</sup>

##### **A. Access to health/mental health services**

- Disseminate and promote use of ASD practice guidelines to define standards of care in health, mental health, social services, and education.<sup>19</sup>
- Monitor the development of ASD service guidelines and incorporate the final product into curriculum for residency, professional certification, and other pre- and in-service training.<sup>20</sup>
- Provide incentives to ensure greater availability of well-trained providers and a more equitable distribution of services across geographical areas.<sup>21</sup>
- Develop an action plan for collaboration at all levels (utilizing the Interagency ASD Coordinating Council) to identify services and address the service needs of persons with ASD within the broader initiatives to develop community-based systems of services for all persons with disabilities.

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<sup>17</sup> “One year ago: two or three local counselors said they didn't think they could help a 14-year-old with ASD with violence issues and mild mental handicap. We tried Indianapolis but son was noncompliant and distance/schedules were an issue.” Consumer Survey, 2006.

<sup>18</sup> Baker, *Autism Spectrum Disorder Roadmap*, 11.

<sup>19</sup> “Doctor encouraged testing for speech, which we did, but he wasn't ‘bad enough’ until re-tested two years later. Thought he just needed speech therapy and patience. Cost contributed to choice not to pursue diagnosis. Teacher suggested he be tested and did through school's special services.” Consumer Survey, 2006.

<sup>20</sup> The Autism Education Network Expert Panel, *National Standards Project*, [project description on line] (accessed 5 December 2006); available from <http://support.autismeducation.net/site/PageServer?pagename=NationalStandards>; Internet.

<sup>21</sup> “We qualify and have two support service waiver slots but *no service providers*.” Consumer Survey, 2006.



## **B. Early intervention services**

- Create an initiative to bridge research and university clinical programs to invest in high-quality models to solve practical issues of provision in Birth to Three Early Intervention Systems in a community setting.
- Create incentives for collaboration between (a) medical waiver providers and private providers, and (b) Individualized Family Service Plan (IFSP) and special education teams.
- Seek federal grants to develop training models for special educators, parents, and other providers.
- Increase funding for early intervention programs including preschool programs.
- Create incentives for schools to provide ongoing training to staff and teachers.
- Create an initiative to build top-down consensus on the need for increased understanding and training around ASD service provision in Indiana schools.
- Increase capacity of speech-language pathologists and occupational therapists.<sup>22</sup>

## **C. Education services under Section 504 and IDEA**

- Search out and apply alternate career/independent living curriculum with goals for self-determination beginning in elementary school.<sup>23</sup>
- Create a mechanism to ensure that Individual Education Plans are effectively implemented.
- Improve the current IDOE monitoring system as it relates to issues of local control and services to children with disabilities.<sup>24</sup>
- Create incentives for schools to develop high-quality programs for students with ASD.
- Ensure children with an educational diagnosis of ASD receive special education support and extended school year services from diagnosis through age 21.<sup>25</sup>
- Mandate state-approved credentials for those delivering therapeutic services utilizing Intensive Early Behavioral Therapy (IEBT) principles and strategies in the educational setting and in private practice.
- Encourage insurance companies and Medicaid waiver providers to reimburse for services provided by credentialed service providers.

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<sup>22</sup> “[One year wait for] *school* speech therapy. Aide not in classroom. He needs to go to resource room for help to communicate his needs—*huge* obstacle.” Consumer Survey, 2006.

<sup>23</sup> George VanHorn and Tammy Ummel, *Results: What Does it Mean for All Students*. (Indianapolis: Presentation at The Road to Results: Indiana Statewide Transition Conference, 2006).

<sup>24</sup> “Not having clear/realistic leadership/support from the state education system, including Mandate with no money; reactive/inconsistent responses to complaints & interpretation of the intent of the law.” Provider Survey, 2006.

<sup>25</sup> Patricia Howlin, Susan Goode, Jane Hutton, and Michael Rutter, “Adult outcome for children with autism.” *Journal of Child Psychology and Psychiatry* June. 2004 45 (2): 212-229.

- Increase awareness and recognition in university educational programs for speech-language pathologists as well as educators and school psychologists of pragmatic language impairment (difficulty in using the social aspect of language) in individuals with ASD who have adequate vocabulary, syntax, and grammar.
- Increase recognition of the importance of social skills development as an educational issue for all students.<sup>26</sup>
- Increase the general education fund to assist schools with the real costs of educating children with ASD when using evidence-based practices.
- Increase availability of evaluations for assistive technology (e.g., augmentative communication devices) and provide appropriate technology to students as needed.
- Require training for staff on specific equipment provided to students to ensure effective use and communication through IDOE funded programs.
- Increase pre-service training in ASD at universities and colleges across the state for both general and special education teachers (Higher Education Initiative).
- Provide appropriate support to teachers and others, including administrators and staff members, who come into contact with students with ASD, including pre- and in-service training, ongoing hands-on classroom support, and resources for providing appropriate education.
- Increase appropriate preparation programs for special education teachers, aides, and general education teachers for instructing students with ASD.

#### **D. Access to Social Services**

1. Integrated service systems/medical home
  - Fully fund systems of care throughout the state of Indiana.<sup>27</sup>
  - Establish wraparound services that build on school programs, including extended-day and extended-year programs, through partnerships with community mental health systems, social services, and other public and private children's services agencies.
  - Create a public awareness campaign to promote the concept of a "medical home" through a collaboration with IDOH, FSSA, and state pediatric associations.
  - Train state providers to understand and increase capacity for providing and/or referring clients to a medical home.

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<sup>26</sup> Mr. and Mrs. I. vs. Maine Sch. Administrative Dist., 106 LRP 5468 (D. Me. 2006).

<sup>27</sup> "On average, systems of care save public health systems \$2,776.85 per child in inpatient costs over the course of a year and save juvenile justice systems \$784.16 per child within the same time frame." Substance Abuse and Mental Health Services Administration, *Community-Based Care Leads to Meaningful Improvement for Children and Youth with Serious Mental Health Needs*. [news release on line] (accessed 10 November 2006); available from [http://www.systemsofcare.samhsa.gov/news/nr\\_index.aspx](http://www.systemsofcare.samhsa.gov/news/nr_index.aspx); Internet.

- Influence intensive and ongoing interagency training on ASD characteristics, behavioral interventions, and other resources available for families.
  - Promote continued parent training through federally- and state-funded training centers.
2. Comprehensive services provided by coordinated multi-specialty providers
- Increase capacity and funding of respite services for families by seeking funding under the federal “Lifetime Respite Care Act of 2006.”<sup>28</sup>
  - Increase behavior management support for families as necessary.<sup>29</sup>
  - Change eligibility requirements for services for adults with ASD with IQs over 70 to consider their social skills and ability to self-support independently.<sup>30</sup>
  - Through grants from DMHA and DDRS, support family- and consumer-driven state and community development initiatives to implement creative approaches to effective practices (i.e., DMHA Transformation Workgroup initiative, IDOE Children’s Social, Emotional and Behavioral Health Plan, systems of care).
  - Provide technical assistance to state agencies and local communities to implement effective service delivery models.
  - Encourage continued IDOE support of web-based resources, family and educator training, Vocational Rehabilitation (VR) training, and information distribution.<sup>31</sup>
  - Ensure that individualized plans coordinate a comprehensive continuum of services and supports across the lifespan, and across all necessary service sectors.<sup>32</sup>
  - Continue to fund and support systems of care across the state of Indiana, and include ASD as a reason for referral.
  - Continue to support the ASD Insurance Mandate.

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<sup>28</sup> “[Three children with ASD: 15, 13, 11] Even after the first (oldest) child was diagnosed, I was told to wait. [Additional delay factor, lack of] availability of respite or caregiver assistants, since there are three children to manage going to a doctor at all. [Referred to options] but no availability of trained personnel to provide treatment.” Family Survey, 2006.

<sup>29</sup> “Never know when he will create a crisis. I have had to do everything in regards to the home, children, cars, insurance, extended family, etc., and there is constant turmoil and frustration. I was not emotionally or physically able to work because of the stress at home.” Family Survey, 2006.

<sup>30</sup> Patricia Howlin, et al.

<sup>31</sup> The most common site referred to as a source for information was that run by the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community. Family and Educator Surveys, 2006.

<sup>32</sup> Indiana Task Force on Autism Spectrum Disorders, [home page on line] (accessed 10 November 2006); available from <http://www.doe.state.in.us/exceptional/TaskForce.html>; Internet.

- Identify and analyze effective models that organize, integrate, and deliver comprehensive services.
  - Develop models that permit providers and families to have systematic access to shared provider records and examples of exemplary practice (IDOE Children’s Social, Emotional and Behavioral Health Plan, Waiver programs, systems of care).
3. Benefits and coverage
    - Include Intensive Early Behavioral Therapy (IEBT) and other services shown to be successful for children with ASD in covered services.
    - Create mechanisms for coverage of habilitative care.
  4. Medicaid and private insurance terms of coverage—diagnoses, medical necessity, and waivers
    - Increase funding to increase availability of coverage by Medicaid and private insurance plans.
    - Establish appropriate, reimbursable Current Procedural Terminology (CPT) codes for ASD and its treatment.
    - Work with insurance companies to increase reimbursement to an adequate level for in-home support for behavioral and other ASD-related challenges.

## V. Organization of Community-Based Services for Easy Use

**Goal: Community-based services will be organized so that individuals with ASD and their families can use them easily.<sup>33</sup>**

### A. Interagency Coordination

- Composition of the Interagency ASD Coordinating Council must include consumers and representatives of consumer organizations who will provide oversight, but be equal partners in the planning, delivery and evaluation of services for persons with ASD, in accordance with the NIF.<sup>34</sup>
- Help state agencies determine effective delivery systems and collaborations for provision of adequate ASD services.

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<sup>33</sup> Baker, *Autism Spectrum Disorder (ASD) Roadmap*, 13.

<sup>34</sup> “In a consumer- and family-driven system, consumers choose their own programs and the providers that will help them most. Their needs and preferences drive the policy and financing decisions that affect them. Care is consumer-centered, with providers working in full partnership with the consumers they serve to develop individualized plans of care. Individualized plans of care help overcome the problems that result from fragmented or uncoordinated services and systems.” President’s New Freedom Commission Report, 2003.

- Increase funding and capacity for trained providers to integrate and coordinate service systems, to eliminate families with members with ASD continually waiting for needed services.<sup>35</sup>

## VI. Successful Youth Transition to Adult Services, Work, and Independence

- Collect data about the life experiences and needs of adults with ASD.
- Start transition planning services early.<sup>36</sup>
- Support the repromulgation of Indiana's Special Education Rules, Title 511, Article 7 with transition remaining at 14 years of age.<sup>37</sup>
- Develop and support skill-building opportunities that promote self-determination in youth with ASD.<sup>38</sup>
- Provide an array of post-secondary services and supports in the community for individuals with ASD with varying degrees of ability.<sup>39</sup>
- Incorporate aging issues into transition planning such as estate planning and long-term care.<sup>40</sup>
- Formalize state partnerships to ensure collaboration across service sectors providing transition planning through the Interagency ASD Coordinating Council.
- Establish accountability among the agencies involved to ensure that the comprehensive plan is carried out.
- Increase initiatives to bring VR up to date on training in working with individuals with ASD on employment issues and customized employment.
- Create accountability/incentives for VR to be involved with transition before students leave high school.<sup>41</sup>

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<sup>35</sup> “[Transition meeting held] after waiting four months after our request; he was in First Steps but they told us he was “OK” and didn't transfer us to the school system . . . I got him diagnosed myself at Riley when he was three years two months. Was never made aware of 0–3 programs by anyone! Withdrew from Head Start. Teacher refused to work with him; said “I refuse to cater to his special needs”! [Not accessing (VR) services because] after several failures has given up.” Consumer Surveys, 2006.

<sup>36</sup> “All other pedagogical activities take a second place until the child demonstrates responsible behavior in the areas of safety, personal grooming, personal hygiene, respect for others and respect for personal property.”

David L. Holmes and Katy Chafee, *Transition Planning for Individuals with ASD*, unpublished book chapter, 2007.

<sup>37</sup> “Each state has the authority to establish its own age for special needs students transition IEP.” David L. Holmes et al.

<sup>38</sup> Teresa Grossi and Cassandra Cole, *Understanding Classroom Practices and Post-Secondary Outcomes*, (Indianapolis: Presentation at The Road to Results: Indiana Statewide Transition Conference, 2006).

<sup>39</sup> Nicolle M. Garza, *Engagement in postsecondary education, work, or preparation for work*. In National Longitudinal Transition Study-2. After High School: A First Look at the Postschool Experiences of Youth with Disabilities (April 2005). (accessed 10 December 2006): [www.nlts2.org/reports/2005\\_04/index.html](http://www.nlts2.org/reports/2005_04/index.html); Internet.

<sup>40</sup> “As a parent—how do we plan for the future? I know this is a very broad statement. We have a Special Needs Trust set up but are more concerned about how we protect all our assets (if we should have to be placed in a nursing home and use up our assets) so they will be there to keep care of him when we are gone.” Education Survey, 2006.

- Increase state capacity of professionals who have the knowledge to assist youth and families in making the transition to work and/or finding financing for education.
- Increase funding and capacity of ongoing treatment services and service facilities for adults with ASD once they turn 21.
- Increase capacity of trained professionals who work in various environments and roles with adults with ASD.
- Increase opportunities for families to educate and support each other and other community members through consumer organizations.

## **VII. Adequate Public/Private Insurance for Children, Youth, and Adults with ASD**

- Demonstrate the cost-effectiveness of early intervention through establishing state-funded research and demonstration grants to state universities/organizations which include multi-university collaborations.<sup>42</sup>
- Expand health insurance benefits for ASD while recognizing the need for a broad array of services.
- Continue to focus on and monitor Indiana's ASD Insurance Mandate.<sup>43</sup>
- Develop model financing and benefit structures for public and private insurance packages and Medicaid waivers.<sup>44</sup>
- Conduct both national- and state-level studies of cost and insurance to determine policies and practices that affect financing, eligibility, and service delivery.
- Adopt innovative approaches to financing. Suggestions might include the use of tax-exempt medical savings accounts, financial planning assistance, or other strategies that blend funding from multiple sources.

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<sup>41</sup> There is no paradigm for scaleable services for people with ASD at this stage. The cost to society for providing these scaleable services will likely be more than repaid by the taxes remitted by recipients earning salaries.

<sup>42</sup> "The Social Costs of Inadequate Education" found the United States loses more than \$50 billion a year in federal and state income taxes for all 23 million high-school dropouts ages 18-67."

Michael A. Rebell, *The Campaign for Educational Equity*, [report on line] (accessed 10 November 2006); available [http://www.tc.columbia.edu/i/a/3082\\_SocialCostsofInadequetEducation.pdf](http://www.tc.columbia.edu/i/a/3082_SocialCostsofInadequetEducation.pdf); Internet, p. 6.

<sup>43</sup> The ASD Insurance Mandate has been challenged every year since its inception and has never covered all persons with ASD for the reasons stated at the national level (self-insured companies, mental-health-related limitations, etc.). Families are experiencing new challenges with insurance companies relating to co-payments and eligibility for reimbursement conflicting with state-provided services, including those provided through public schools for educational purposes. Ongoing monitoring of this situation, as well as working with the Indiana Department of Insurance (IDOI) and state legislators, will be critical for some time to come. Commentary from Autism Society of Indiana, 2006.

<sup>44</sup> "Reverse discrimination: We do not qualify for Medicaid and thus are turned away from services and programs which are Medicaid-funded. These same services and programs also are not covered by traditional insurance. But we need some of these services and programs. Private pay would only allow a small fraction of what is needed." Educational Survey, 2006.